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AUTHOR Keeling, Maud; And Others
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ABSTRACT

The pamphlet describes three Hogg Foundation-funded Texas programs (one exclusively hospital-based, one hospital-based with extensive linkages to community resources, and one community-based) which serve predominantly high-risk, low-income Mexican American families. First described are social work services connected with the Driscoll Foundation Children's Hospital Neonatal Unit, which serves Corpus Christi and a large, sparsely-populated rural area, with many newborns referred by physicians in surrounding counties. The article notes that parents cannot always accompany children to the hospital, so social workers provide crucial support for parents experiencing separation from infants during hospitalization, death of an infant, or prospects of lifetime care for severely-disabled infants. Austin's Program Padres e Hijos (Parent-Child Program) is described as a low-cost project emphasizing nonformal, in-home education based on the cultural values of the Mexican American community to enhance parenting skills and promote physical and mental health of infants. A final article discusses the Mexican American Preterm Project (San Antonio), which concentrates on infants weighing less than 2 1/2 pounds at birth, and aims to identify the needs of parents with regard to their newborns and enhance family stability by providing consultation and referrals to specialized service programs in the community. (MH)

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HOPE FOR HIGH RISK INFANTS AND THEIR FAMILIES

A Glimpse at Three Demonstration Projects

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HOPE FOR HIGH RISK INFANTS AND THEIR FAMILIES

A Glimpse at Three Demonstration Projects

Social Work Services to the Neonatal Unit
at Driscoll Foundation Children's Hospital

The Parent-Child Program
Center for the Development of Non-Formal Education
Centro para el Desarrollo de la Educación No-Formal—CEDEN

Mexican-American Preterms
Parenting and Development over the First Year

by
Maud Keeling
Emily Vargas Adams
Diane Hawk Spearly

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The University of Texas
Austin, Texas 78712

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Preface

Child development research has shown that the preschool years are the cornerstone for subsequent cognitive and emotional maturation. Consequently, a number of social action and evaluation programs have been conducted, with private and public funding, in an attempt to discover effective ways to stimulate psychological growth in infants and young children.

Programs have usually taken the form of early treatment rather than actual primary prevention activities. Various national experiments have attempted to assess the influence of early education programs as critical factors in children's emotional development. Evaluation data from parent-child programs have shown that the mother's skills as a parent have a significant effect on the child's intellectual and social development by age three. Thus, by designing programs to improve these critical parenting skills, the outcome could be the subsequent enhancement of the child's development and the reduction of risk for mental health problems as well as for educational failures.

In general, parent education programs have shown that by age three there are very large individual differences in abilities among children, particularly between children of diverse socioeconomic backgrounds. Research also suggests that a child's early development of intellectual, social, and motivational abilities can be significantly influenced by the child's early environment, especially the home, and the child's major caretaker. In addition, it has been found that a special set of stresses and problems often prevent the mother in a low-income family from contributing all she might to her child's development. These problems may include lack of economic resources, limited access to health and mental health care for her family, lack of transportation to needed resources, substandard housing, and inadequate nutrition.

Specific environmental conditions may also have direct impact on parental capabilities and functioning. Within urban areas, inner-city families may lose contact with the stabilizing forces of their particular traditional culture. Conversely, families in sparsely populated rural areas face geographic

isolation and the paucity of financial and human resources. Such conditions compound stresses on the entire family and increase the risk of mental health problems for all its members.

Another group that has become a focus of concern is the "high-risk" parents, where either the parents' or the child's living or developmental abilities are threatened. Concomitant problems may multiply the crises. For example, pregnancy during early adolescence and low-birth-weight infants frequently occur together. Low birth weight is a major cause of birth injuries and neurological defects. Not only does the teenage mother have to adapt to change in her normal course of development, but she has the additional demands of caring for a baby. National and state studies have found that when threatened by low income, low educational attainment, and poor nutrition, individuals are at high risk for mental and physical distress.

Photo by Patricia Platt

In Texas, over one-third of the Mexican-American families fall below the adjusted poverty line. The Mexican-American, then, is at an enormously high risk for physical and mental problems. However, while Mexican Americans have been overrepresented as members of lower socioeconomic groups, they have been underrepresented in utilizing health and mental health programs.

The Hogg Foundation has directed its interests to exemplary activities that promote and enhance the health and well-being of individuals and families in order to attempt to reduce the likelihood of problems described previously. The challenge has been how to teach people to become partners in the protection of their own health. The problem is how to create a cultural milieu in which responsibility for one's health is a personal value.

For example, the adverse effects of a premature birth, a congenital defect, or an impoverished environment can be minimized through carefully-designed programs that educate parents about infant development and provide essential emotional support. A secondary benefit is that such programs expose families to otherwise unknown community resources. Given these types of assistance following a high-risk birth, family members may experience individual growth and interpersonal closeness, thereby reducing chances of dissolution of the family unit. Those temporarily handicapped by impoverished environments may begin to break out of their prison of despair and emerge with new knowledge and dignity.

Subjects of this publication are three Hogg Foundation-funded programs which serve predominantly high-risk, low-income Mexican-American families. One is exclusively hospital-based; another is hospital-based but with extensive linkages to resources in the community; and the third is community-based. The programs differ in structure and function, and their funding base includes both public and private sources.

The Driscoll Foundation Children's Hospital Neonatal Unit serves Corpus Christi, Texas, and a large, sparsely populated rural area with many newborns referred by physicians in surrounding counties. Neonates needing specialized care are transferred to this intensive care unit from local and surrounding hospitals. Because of limited resources, geographical distance, and other familial obligations, some parents cannot accompany their children to the Driscoll Foundation Children's Hospital. A social worker provides

crucial support for parents experiencing the trauma of prolonged separation from their infants during hospitalization, the death of an infant, or the prospects of lifetime care for severely-disabled infants. Referrals for continuity of treatment are made back to the community of residence.

Based at a teaching hospital in San Antonio, the Mexican-American Preterm Project has as its target population infants who weigh less than two-and-one-half pounds at birth. It is designed to address the physical and mental health problems accompanying premature births. A primary goal of the program is to identify the needs of the parents with regard to the newborn infant and to enhance family stability. The infants receive periodic developmental assessments and comprehensive medical care from birth to two years. Consultation is provided to the parents and supplemented by referrals to specialized service programs in the community.

The *Programa Padres e Hijos* is well-established in the Mexican-American barrio of east Austin, Texas. This low-cost project emphasizes nonformal, in-home education which is based upon the cultural values of the community. A three-pronged approach of education, nutrition, and health is used to enhance parenting skills and to promote physical and mental health. Research and evaluation components assess various intervention models and bilingual and audiovisual materials in human growth and development.

While primary prevention and health promotion place a focus on the community at large, finite resources do exist in these austere times; therefore, one strategy is to allocate resources where they will be effective by highlighting populations at high statistical risk. Thus, the developmental model is a good one to use, from future parenthood through childhood, adolescence, adulthood and aging. By learning from the evaluation of these demonstration programs, perhaps other cost-effective models may evolve.

Sources

Statistical data for this introductory statement were extracted from:

Annual report to the Hogg Foundation, "Longitudinal Follow-Up Study of Parent-Child Education in Mexican Families," Parent-Child Development Center, Houston, Texas, 1977.

Blum, A., Ellir, R., Marshall, R., McDonald, R. J., Rodríguez, R., and Warner, D. *The Health of Mexican Americans in South Texas*, Lyndon B. Johnson School of Public Affairs, Policy Research Project Report No. 32, The University of Texas at Austin, 1979.

Teller, Charles H., Rodríguez, Romeo, and Clyburn, Steve. "Physical Health Status and Health Care Utilization in Texas Borderlands," mimeo, University of Texas, April 1975.

U.S. Department of Health, Education, and Welfare, National Center for Health Statistics. *Preliminary Findings of the First Health and Nutrition Examination Survey, U.S., 1971-1972, Anthropometric and Clinical Findings, 1975*. Also, U.S. Department of Health, Education, and Welfare, Health Services and Mental Health Administration, *Ten State Nutrition Study, 1968-1970*, Center for Disease Control, 1972.

Social Work Services to the Neonatal Unit at Driscoll Foundation Children's Hospital

by Maud Keeling

On the bench outside the ICU for newborns, a man sat hunched over his knees, his hands covering his face. The social worker touched his shoulder and asked if she could help. "Do you have a baby in there?" The man sat up, smoothing tears from his eyes with his fingers. His face was weathered and lined. "Yes. It's my son's baby. My son is working on an offshore rig, and we can't get in touch with him. He arranged to be off when the baby was due, but it came early. My wife is at the other hospital with our daughter-in-law because she was so upset when they told her they were bringing the baby here. I came in the ambulance because this is my grandson—but I don't know what to do."

In the Social Work office, calls were placed to the father's employer and some concerned family members. Arrangements were made to have the father returned to the mainland by helicopter. Then the social worker and grandfather talked to the doctors and visited the baby. Pride welled in the old man at the sight of the infant. Even though it was very tiny, it was his first grandchild, and it was a boy. He seemed to be reassured about the once-frightening-looking machines, wires, tubes, and needles after the nurse explained the function of each and the reason for it. When he left the side of the warmer he said, "He surely will live. There are so many who want him and who love him very much."

The father arrived late that afternoon. He bent over the baby's warmer and beamed with joy to feel the tiny fingers circled around his own. The social worker snapped the instant camera and gave him the picture. She asked him to take the photo to his wife and explain to her each piece of equipment on the baby just as the nurse had explained it to him. The next day the social worker called the mother to report how the baby was getting along and to encourage her to call the unit twice a day to talk to the baby's nurse. The mother told how glad she was to have the picture and how eager she was to see and hold the baby.

Director of Social Work
Driscoll Foundation Children's Hospital

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The Hospital, the Infants, the Families

A neonatal intensive care unit serves infants needing special physical care, babies with high-risk factors in their births. While medical teams struggle with problems of the infants, family members have special needs for support, also. The social, emotional, and mental health problems associated with the birth of high-risk and ill infants are too often overlooked in the crisis of providing intensive care for the newborns.

Special problems of parental acceptance, parent-infant bonding, and the handling of anxiety and grief by family members are addressed in a program within the Newborn/ICU at Driscoll Foundation Children's Hospital in Corpus Christi, Texas. The unit's social worker is a living link between families, critically-ill newborns, and the hospital's medical staff. The goal for each family is to attain some resolution of the initially-defined problems by the time the baby is discharged.

The unit at Driscoll Hospital is the only level III newborn nursery within a 150-mile radius. Situated in the center of the "Texas Coastal Bend," it is a pediatric critical-care center for the whole southern section of the state below San Antonio. Babies are rushed from general hospitals in the city or from towns many miles away. The mothers must remain in the hospitals where they were delivered. They are terribly frightened for the babies which have been taken from them. Fathers or other relatives may accompany the infants. During crisis, the social worker is available to family members and the staff to further each one's understanding of details of the situation and his or her emotional reactions to it.

Before the program received a three-year grant from the Hogg Foundation for services of the neonatal unit social worker, a practicum student and the hospital's Director of Social Work covered the unit on a trial basis, documenting the need and developing a service model. The Driscoll Foundation and the hospital itself have agreed to fund the social work position at the end of the pilot period if the project's value has been clearly demonstrated. The Polaroid Foundation contributed a camera and a supply of film.

Data collection and analysis of the first three years of Social Work Services to the Neonatal Unit reveal that the difficulties of families are: (1) emotional problems, (2) family instability, (3) need for follow-up care, (4) need for

greater bonding, (5) physical problems of the mother, (6) death of the infant, (7) inadequate economic resources. As the hospital receives more critically ill infants, more families tend to have multiple problems.

In the three-year grant period, there were 1217 admissions to the neonatal unit. Thirty-two percent of these were from outside the county—from 22 outlying hospitals and a small number of deliveries at home. Eighty-five percent of the parents listed some type of employment, but only about half were covered by private health insurance. Much of the work force in this area is engaged in seasonal, hourly-wage occupations which do not offer employee benefits such as health insurance.

The ethnic background of the infants reflects the general population mix of South Texas—59 percent Mexican American, 38 percent Anglo, and 2 percent black. The majority of the babies stay for 15 days or less, but about 12 percent remain in the hospital for a month or more. Of the 404 infants admitted during the most recent one-year period, almost three-quarters had good prognoses on discharge. About 5 percent had long-term defects and poor prognoses. Thirteen percent died, most of whom were very premature or were babies with serious congenital anomalies.

Support for Families in Crisis

A closer look into the social worker's activities and accounts of actual cases may help in understanding this professional's role. Shortly after a baby is admitted to NICU, the social worker photographs the baby in its warmer or isolette. If the mother is in a local hospital, the social worker visits the mother there, usually the same day as admission, and gives her the baby's picture. They talk about the newborn and about life in the NICU. The various equipment on and around the baby is explained, thus preparing the mother for her first visit to the unit. The social worker's visit usually helps to allay some of the mother's initial anxiety. Mothers in outlying hospitals are contacted by telephone, and the photograph is mailed to each mother or is given to a family member to take to her.

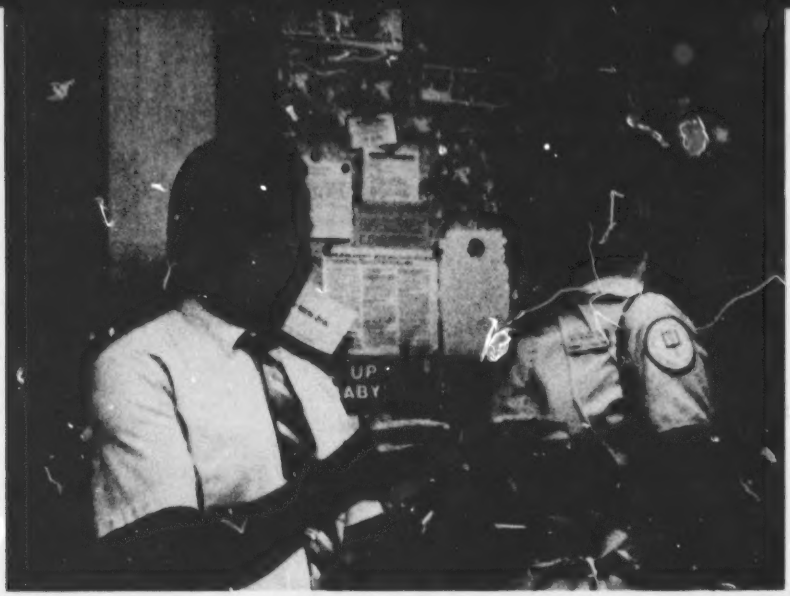
After the initial visit, the social worker and family maintain contact of varying intensity depending on the severity of the problem and the crises which arise. Typically there are many brief contacts such as calls to report on

the child's condition or encouragement to the parents to touch and talk to the baby during a visit. Intensive contacts might be described as those in which some actual change takes place in the parents or the family in relation to the infant as a result of the social work intervention. For example, the social worker may help a parent to release anger, express guilt, to grieve, to accept the baby's condition, or to decide about keeping or placing a severely defective child.

Work with families changes as babies improve and are moved from the intensive care unit to a convalescent section. At this stage, contacts may be fewer, and they center around bonding and plans for going home.

"Bonding," a term used by infant development specialists, refers to the process by which parent and child develop a mutually satisfying attachment to one another. Through intimate exploration such as face-to-face communication, touching and feeding, the mother or father and child build a pleasurable, unique system of communication which serves to keep them physically and psychologically close during the years when the infant is totally dependent on others. The unusual conditions of ICU infants sometimes prohibit the natural closeness of parents and their babies. Therefore, parents are shown how they can hold, look at, talk to, and care for their infants who may be tiny, disfigured, or attached to monitoring or life-sustaining equipment.

A mother gently strokes the tiny leg of her premature, 850-gram baby (less than two pounds) in the neonatal intensive care unit. This kind of touching is central to the bonding process. *Photo by Maud Keeling*



The social worker gives a photograph of an intensive-care infant to a proud father. He will take it to the mother who is hospitalized elsewhere. *Photo by Maud Keeling*

The photograph which the social worker takes of the baby after arrival in NICU is an important element in bonding. It is very often the mother's first visual image of her baby. It confirms to her the reality of this new person which she has not experienced since the birth. It provides her with a representation of her child to which she can begin to relate. Seeing her baby in the NICU environment enables her to share her child's experience, a vital need in bonding, especially when mother and baby are separated. The picture of the baby has a significance to the mother far beyond the expectations at the beginning of the program. In speaking about it later, many mothers have expressed the feeling that once they saw a picture of their baby, they could "begin to love" the baby. The photograph seems to enable the mother to direct her desire to nurture and her feelings of affection to the baby immediately without holding back these feelings until she is able to visit the infant.

Although the social worker most often deals with anxiety at the panic level, he or she also deals with grief. A family grieves when its baby dies. They also grieve when a baby is born with a defect—grieve for the loss of the perfect child they had expected.

The social worker has found several practices particularly useful when parents experience the death of an infant. The closer the parents become to the child while alive, the more successful the grieving process. Therefore,

parents at Driscoll are first encouraged to become fully, emotionally involved and bonded to their infants despite poor prognoses. If possible, the parents are present and may hold their infant at the time of death. A quiet, private place has been arranged where parents may grieve with the body of their child. For ill or distant parents who have never had the opportunity to be with their infant before death, the picture taken by the social worker for the family helps them to progress through the adaptive states of grief.

One grieving parent wrote:

> May God bless you for your thoughtfulness, kind words, and for being there when we needed someone to answer our questions . . . I felt you really share my sorrow. Thank you for allowing me to hold my angel in my arms while he was still alive. I shall never forget the joy I felt . . . Please pray for us that . . . we may someday have another baby, a baby we can share our lives with . . . It's people like you that help others be able to bear life's hardships.

Two Family Cases

For the family that suddenly has a handicapped child, other kinds of support are necessary. A baby boy was admitted with Myelomeningocele (an opening into the spine caused by a protrusion of the spinal cord through a defect in the verterbrae canal). He underwent surgery for repair of the defect. Extended family members were far away, and the father and social worker waited together during the surgery. While they waited, they explored the father's understanding of the baby's medical problem and his feelings about having a handicapped child. Shock was the dominant feeling. Having a six-year-old, the parents had been through the birth experience once and were not prepared for the possibility of a defect with this birth.

The mother, discharged from her own hospitalization, arrived the next day. She was encouraged to touch and look at her baby and was told she would be able to hold and feed him. She expressed fear and concern about caring for her son. She asked if she could talk with a parent of another child with this problem. She read the pamphlets on spina bifida that were given to her. Arrangements were made for her to talk with the president of the Spina Bifida Association. Initially this meeting was more upsetting than helpful to the new mother, as the older child had more serious problems than were

The social worker encourages a parent to help care for her recovering infant.
Photo by Maud Keeling

anticipated for the new baby. Later, however, the support given the family did help them to understand their child's prognosis and his medical needs.

Much attention was given the mother during the patient's stay because the father's traveling job kept him away during the week. Counseling helped the mother cope with surgery to insert a shunt that would drain fluid from the baby's head. The mother adjusted well to the baby and felt comfortable caring for him when he was discharged after a month and a half in the unit. Referrals were made to the Spina Bifida Clinic and Infant Stimulation Program, and a Public Health nurse was assigned to visit the patient and family at home after discharge.

* * *

In some cases, the family situation surrounding the birth is problematic. Two frightened teenagers—a 14-year-old mother and a 16-year-old father—wrapped their newborn baby in a blanket and abandoned it in a field, thinking the infant was dead. Upon learning of the birth, both sets of

grandparents hurriedly took the baby to Driscoll Hospital while the mother was treated elsewhere.

Because of the initial neglect, the Protective Service of the (Texas) Department of Human Resources was notified by the social worker, who assessed the family's capabilities. She counseled them on options including long-term counseling for the mother, placing the baby for adoption, or custody by the grandparents. Decisions were made after her work with all parties helped them develop realistic insights.

Conclusion

The actual services of the social worker might be summarized under the broad headings of counseling, teaching, and referral. In addition, the social worker assists with many "concrete services" such as the securing of permits for medical procedures and helping families with lodging and transportation. Besides assistance to families, the social worker brings a unique contribution to the patient care staff. Social work assessments aid the medical staff in planning treatment and follow-up care for the infant. By example, the social worker demonstrates to the staff ways to aid families in crisis. He or she also helps the staff directly with their own emotional reactions to the death of an infant or other difficult circumstances.

In providing social work services to this special group of families and the professionals who care for their babies, it has been found again and again that in times of crisis, individuals often discover inner resources and support from others they were unaware they had. The social worker's skill and caring can help to turn a crisis into an opportunity to develop greater strength and confidence to meet continuing challenges. When this happens, a major goal of this program is met.

The Parent-Child Program
Center for the Development of Non-Formal Education
Centro para el Desarrollo de la Educacion No-Formal—CEDEN

by Emily Vargas Adams

Little Jaime lay quietly in the gray dresser drawer which served as his crib. He rarely made sounds or cried, and his mother, Angelina, described him as "a very good baby." At nine months, Jaime could not sit up by himself and seemed to be totally uninterested in events around him.

He had nothing in his dark room to look at except cracks in the walls, falling plaster, an old calendar, and torn blue sheets draped over the windows. Placed occasionally on his parents' sagging bed, Jaime would lie still and not even try to roll over. He had the developmental level of a three- to four-month-old baby. At first it was feared that he might have some brain damage or other handicap. However, after thorough testing and observation, he was found to have a good potential for improvement, even though he was very passive and delayed in his development.

Jaime often had diarrhea and suffered from frequent colds and earaches. These conditions were due especially to his poor diet of watered-down milk mixed with cereal and the lack of heating other than a gas stove in Angelina's small home. Because of her isolation from others, Angelina did not know about any local health, nutrition, or social services which could help her family. Furthermore, as a Mexican American, she was proud not to depend on any agency. Since she spoke mainly in Spanish, she was afraid to go places where English was used.

Home life was hard. Angelina's husband, Juan, was frequently unemployed because construction laborers could not work when it rained. Often, after they had paid their rent and utility bills, little was left for food and other essentials. Their tiny two-room house was hard to find since it was wedged behind an old duplex on Chicon Street.

Their problems, their needs, their little Jaime were all invisible to the outside world.

Even though Jaime had been a normal infant at birth, by 9 months of age he was

Malnourished, frequently ill, understimulated, passive, and developmentally delayed.

Some 52 percent of the infants and children were developmentally delayed upon entry into the Parent-Child Program of the Centro para el Desarrollo de la Educación No-Formal (CEDEN). Jaime was one of the fortunate children in the low-income barrio of Austin, Texas, whose mothers enrolled them in the program.

When Inés Caballero, a CEDEN home visitor, first saw Jaime, she feared that he might not respond to efforts to improve his development. After testing him carefully using the CEDEN Infant Development Assessment Scale, she was relieved to find that he had an adequate basis for improvement, given a dedicated effort by his parents. After weighing and measuring Jaime, Inés was worried about his slow growth rate.

Her assessment of Angelina's relationship with Jaime revealed that she was a loving but sometimes harsh mother. Angelina rarely spoke to Jaime though she would shout at him, especially when family needs had her worried. She thought her child was "slow" but well-behaved, and she strived to keep him clean even though the house was dirty. Angelina had no learning toys for Jaime.

Inés also found that Angelina knew little about her child's changing nutritional, health, and stimulation needs. During their first visits, Inés discovered how lonely, fearful, and uncertain Angelina was as a wife and mother.

On the basis of her assessments, Inés decided that reinforcing both parents' self-image was a way to guide them in improving Jaime's developments. She taught Angelina to observe Jaime's abilities in order to respond well to his interests and needs. Inés planned her home visits with great care, emphasizing a series of specific areas where Jaime was particularly weak in his development.

Affective development. Inés encouraged Angelina to hold and cuddle Jaime more often, while maintaining firm disciplinary control—as was her way. Angelina brightened and decorated her home, making it a happier place for all.

Perceptual development. Inés showed Angelina how to make a mobile and toys for touching and to use them creatively. Angelina made several learning toys and shared them with other mothers in the program.

Fine motor development. She showed Angelina how to use household objects as toys for developing Jaime's hand-eye coordination, and Angelina created a play area in her kitchen for Jaime.

Gross motor development. Her demonstrations of simple, effective infant exercises brought joy to Jaime and to Angelina, who was surprised by her ability to help her son gain strength.

Language development. Inés encouraged Angelina to talk often to her child, mimic his sounds, name household objects, and give explanations for her actions. Angelina made a special book for Jaime which they especially enjoyed together.

Cognitive development. She showed Angelina how to play with Jaime, make things disappear and reappear in order to help him learn that hidden things still exist, roll balls to him, fit plastic cups together, and put things into kitchen bowls. Angelina took great pride in seeing her child use the opportunities for learning new concepts and in observing his rapid progress.

Inés and Angelina worked together to obtain assistance from health, nutrition, and social services. Angelina gradually lost her fear of agencies and learned to use them wisely for the benefit of her child and family. They also discussed basic knowledge about child care, using the CEDEN Health and Nutrition packets. From their dialogues, Angelina learned to reduce the severity and number of Jaime's illnesses, as well as to improve his diet.

A close bond grew between the two women, and Angelina eagerly awaited the weekly visit of her friend Inés. By reaching out to other mothers during the CEDEN monthly group sessions, Angelina began to develop a support and exchange network. She also gave to her Parent-Child Program by volunteering to make toys and even sent tamales to the staff at Christmastime. Angelina shared her knowledge with two neighbors, one of whom enrolled

in the program. These exchange relationships helped her growing sense of competence and self-worth.

After six months in the program, Jaime not only could stand, but he could also walk and run with a wobbly gait to his mother's open arms. He would often push a chair to the window in order to climb up and watch happily for Inés to arrive. He would speak in short sentences and had learned to name three colors. Jaime was proud to be able to stack small boxes of varying sizes in sequence, put together homemade puzzles, and play other learning games with Angelina and Juan. His anemia was gone, and he had developed an excellent appetite for his now balanced diet that Angelina lovingly prepared for him. He was growing at a normal rate.

Already proud parents, Angelina and Juan eagerly awaited the birth of their second child. Angelina often said she wanted Inés with her when the baby was born, "Just to be sure we do all we can to help our baby from the very start."

Inés would be there.

The Need

Angelina and Jaime exemplify the many severe problems, needs, and stresses commonly found in low-income Mexican-American homes throughout Texas. CEDEN research has shown that various environmental risks lead to developmental delays in children 0 through 3 years of age. Such delays are correlated with one or more of the following:

- poverty-level family incomes
- unstable incomes
- dependency upon social services
- illiteracy
- 8th grade formal education or less
- rural origins of the family
- migrant status
- three or more household moves during the preceding three-year period

Without some intervention, children born in homes like Jaime's will

. . . experience learning problems in school and incur high costs to society especially in their special education requirements

. . . drop out from school, as their parents did, between grades 6 and 8

. . . enter the job market as unskilled laborers and/or lead lives of dependency upon service agencies

. . . possibly become drifters, criminals, drug addicts, alcoholics, or otherwise alienated from society.

Educational and service programs for low-income families are urgently needed throughout Texas to prevent and reverse developmental delays in children during their crucial first three years of life.

The CEDEN Parent-Child Program

The Parent-Child Program/Programa Padres e Hijos is an innovative response to this challenge. As an integrated education and service program, it focuses on the three main areas of children's essential needs:

A home visitor demonstrates appropriate play for the child's level of development. *Photo by Patricia Platt*

Home visits are conducted on a weekly or biweekly basis, and the whole family is included insofar as possible. The home visits are complemented by monthly group meetings, learning toys from the lending library, assistance in gaining needed health and social services, various bilingual educational materials and media, and a comprehensive evaluation system.

The activities are conducted by well-trained home visitors from the local community who make the program relevant to the families and understand their needs and problems.

The CEDEN program model was designed to be replicable, with adequate staff training, materials, and evaluation. It was derived from over 20 years of program experimentation in the United States, Europe, and Latin America. The model was created and adapted to the Austin setting in response to the need for comprehensive, culturally appropriate services to low-income families.

CEDEN also designs, produces, and distributes its own culturally-appropriate educational materials and media, as well as evaluation and research systems. The Center conducts statewide training workshops for early childhood education and social service agency personnel and home day care providers.

Program Impact

The results have been outstanding. Forty-one percent of the children upon entry evidenced developmental delays and many others were "at risk" of delay. After six to seven months, 84 percent were above norms expected for their age.

Equally significant was the finding that the program was as beneficial for children from very poor families as for those with more adequate incomes. The participating families in the CEDEN program had a wide range of income levels, from near indigency to a stable income approaching the middle-class level. Yet the program had a uniformly positive effect upon children and families across all income levels.

When a parent and child enjoy a book together, social interaction, language, and visual recognition skills are promoted.
Photo by Patricia Platt

A mother encourages her child's cognitive and motor development through play.
Photo by Patricia Platt

Other results were similarly positive. Mother-child interaction improved in quantity and quality. Home stimulation levels improved by 25 percent. Mothers' knowledge of infant development, health, and nutrition also rose. Upon entry, only 28 percent had an adequate score, and by program exit 70 percent reached adequacy. Mothers rated the program very highly, and the dropout rate of 9 percent was surprisingly low.

Furthermore, the Parent-Child Program model is low in cost and is cost effective. The expense per month per child was approximately $34.00 in 1983, compared to less comprehensive programs which ran to more than $125.00 per child each month.

Finally, program coverage was striking. In addition to 83 children enrolled, 30 other preschoolers and 300 adults and older siblings were directly included in the program. They, in turn, assisted over 811 additional adults and children who wanted to learn from the program. This indirect coverage has led to major changes in the level of child development and local service usage, and an increase in breast-feeding has also been noted.

The Future

The CEDEN staff plans to expand its program locally. Currently 120 children are enrolled in Austin. Such expansion requires gaining a stronger, long-term base of funding support. Also, the Center is beginning to provide advisory services for program replication in Texas, other states, Puerto Rico, Mexico, and other countries.

More statewide training workshops for program personnel and home day care providers are being held. These are complemented by the bilingual educational materials and media designed and produced by CEDEN. Advisory services are also being provided for planning and conducting comprehensive evaluation and monitoring efforts.

Thus, CEDEN is evolving from its community base into a strong educational and service development center. Ultimately, its staff seeks to assist with policy planning processes which will lead to meeting the needs of parents like Angelina and Juan. Children such as Jaime *can* be helped—the CEDEN Parent-Child Program has demonstrated the effectiveness of various methods for preventing and reversing developmental delays. However, state and community support for parent-child programs is necessary in order to meet the needs of *all* of our children.

Mexican-American Preterms
Parenting and Development Over the First Year

by Diane Hawk Spearly

The DeHoyos Family

Mrs. DeHoyos was apprehensive when she brought baby Carla into the clinic. It was always so difficult for doctors to examine Carla. Her small, round face would wrinkle as she fretted and tossed around. Her mother felt so helpless and sometimes all she could do was "let Carla holler." Today Sara, the developmental specialist at the clinic, explained that some babies get active and fussy because they are very sensitive and become easily overstimulated. Swaddling and vertical rocking can help these babies to calm down.

Carla was born two months before term. Even adjusting her age for an early birth, at five months she was slow in learning to use her hands and fingers. Her predominantly clenched fists prevented her from grasping, a frustrating experience. Sara showed Mrs. DeHoyos how to help Carla by manually opening a fist and placing a toy in the open hand. Then Carla could hold on briefly.

Over the next half year, Mrs. DeHoyos and Carla met with Sara several more times when they came to see the clinic doctors. Sara noticed Carla continued to be an unusually vigorous infant who needed caregivers' aid to calm down in order to function well. Carla would expend large amounts of energy trying to coordinate small movements or making hard, fast movements. This led to fatigue and irritability. Although testing showed her overall development was within the normal range, Carla had difficulty using both hands, standing on her feet rather than her toes, and in synchronizing her arms and legs in crawling.

Mrs. DeHoyos could always report what Carla could *not* do as well as what she had accomplished. The mother would talk of other babies in her extended family—one baby walked at eleven months, another was toilet trained at nine months. Given Mrs. DeHoyos' concern about her daughter's progress, Sara discussed with her the tremendous individual differences which exist with the normal range of development. They also talked about

allowing the individual baby to "tell" the parent when he or she is ready for greater independence. A home visit was scheduled to provide further opportunity for Mrs. DeHoyos to ask her concerns. Other team members reassured her that Carla's current developmental status was healthy, normal, and unique.

By ten months of adjusted age, Mrs. DeHoyos reported that Carla was "getting into everything" and was attempting to stand by herself. Carla's mother seemed pleased with her daughter's abilities and appeared much less anxious than before.

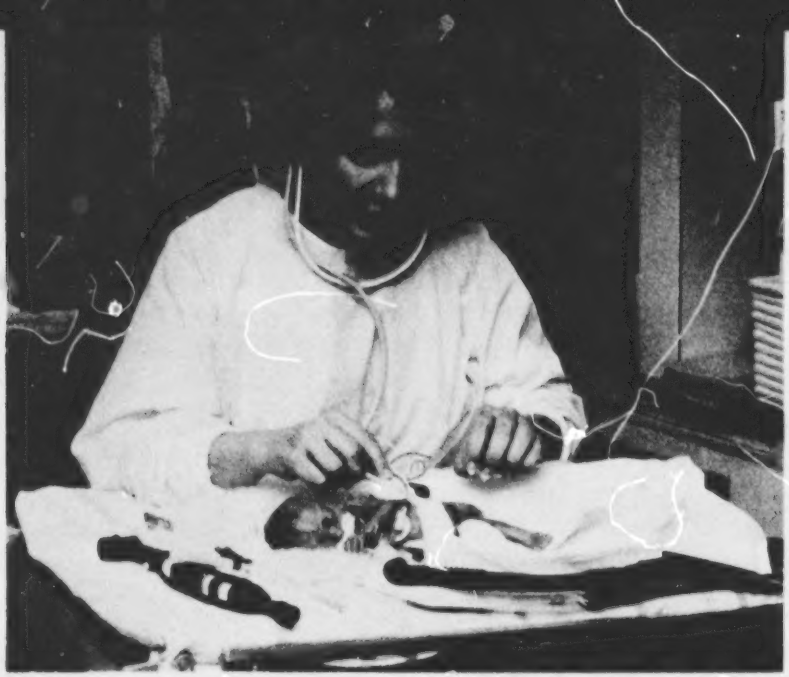
Carla DeHoyos and her mother exemplify the experience of many families in the program. The director explains:

> A major goal of the program is to help each family understand that its baby is a little different. Since these babies were born before they were supposed to be, they are not as mature at birth as a full-term baby. Therefore, they don't achieve the normal developmental milestones—reaching, sitting up, walking, etc.—at the same age.
>
> This doesn't mean that the baby is retarded. The baby might be quite normal—it just needs "credit" for the number of weeks it should have stayed in the womb [adjusted age]. Other babies need special stimulation.
>
> We try to help parents help their individual baby reach his or her maximum potential.

The Program

At the Bexar County Hospital in San Antonio, Texas, the High Risk Infant Program, funded through the Texas Department of Health, provides a continuum of care from birth to one year for infants born prematurely or with other special problems. Without this program, many low-income, high-risk infants would not receive any medical care or immunizations. Unassisted, they would likely develop medical problems.

Concerned about a select group of very high-risk infants, the medical staff focused its attention on babies weighing less than two-and-one-half pounds at birth. A specialist in child development donated one-half day per month to meet with these infants and their parents. She discovered developmental problems among the infants and misunderstanding and worry on the part of



A neonatologist, the associate director of the program, examines one of the many premature babies in her care. Focus is on infants weighing less than 2½ pounds at birth. *Photo courtesy News and Information Service, The University of Texas Health Science Center at San Antonio*

parents. Even more distressing was the fact that children who were located about a year after dropping out of the special two-year follow-up program frequently showed developmental delays. It was frustrating to see a great need for intervention and supportive family counseling that could not possibly be provided to 80 to 130 families within the limitations of four hours per month. As the associate director said, "We realized we weren't even scratching the surface."

Having documented the need, a neonatologist and Associate Director of the program requested funds from the Hogg Foundation for Mental Health to support the child development specialist's services on an expanded basis. The grant made possible additional developmental assessment and family intervention in comprehensive medical care being offered.

Participants

The parents participating in the program are predominately young, married, Mexican-American, bilingual, and poor. The child is usually their first or second, and the family rarely receives financial assistance despite its low income.

The family receives much attention right after the birth when the infant's medical condition is most critical. Then, while the infant is convalescing in the hospital for two or three months, one nurse is assigned to find out how the parents are feeling, how they relate to the baby, what needs are not being met, and how the program could be improved from the parents' point of view. That nurse also helps mothers and fathers develop greater self-confidence in their parenting skills which encourages bonding and helps the transition to home care.[1]

Prior to discharge, the visiting nurse who will be in close contact with the family for the next two years helps the parents prepare the home environment for the infant. Since parents are often apprehensive as well as excited, she can let them know what to expect by sharing with them experiences and suggestions of other families she has previously aided.

Even if a parent has been feeding, bathing, and caring for the infant in the hospital, the early trauma of failure to breathe or eat when the infant's reflexes were immature may still be present in the minds of the parent. Before the baby leaves for home, the child development specialist performs the Brazelton Neonatal Assessment of the infant with the parent present. Interaction with the infant during the exam shows how the reflexes of the baby have matured. It is amazing how well-equipped infants are by this time, normally the time of a full-term delivery. For example, in order to sleep they shut out loud sounds or bright light; in order to learn about their world they look at certain kinds of objects attentively. Individual infants vary in the degree of consolability; responsiveness to sound, light, and touch; irritability; self-quieting; and other behaviors. Each infant's characteristics and capabilities observed by the parent indicate the style and kind of care needed at home.

Before leaving the hospital, the entire clinic team—the neonatologist, the home visiting nurse, the nurse who coordinates clinic appointments, and the child development specialist—meets with the family to offer their services. If willing, the parent signs a contract specifying the components of the program and their own participation. The contract and the outstanding efforts made to stay in touch with each family by phone or in person have led to the continued involvement of 90 percent of all families who enter the program.

The family is visited soon after the infant goes home, a crucial time of adjustment. The nurse is also available by phone. Some mothers have called with questions as often as three times a week during that first month at home. The home visiting nurse or casemanager is the family's personal link with the clinic. This person's concern and availability humanize the family's experience in the program. The familiar face and way of relating greet the family at every clinic visit.

These clinic visits are scheduled about every three months for immunizations and other preventive care. And, of course, the family brings the child in for treatment of illness. If the child needs special services, the family is referred to appropriate community resources such as intensive infant stimulation programs, the Cerebral Palsy Center, physical therapy offices, and family mental health services. With parents' permission, medical and developmental records of the child are shared with cooperating agencies.

The child's ability to reach and grasp is elicited as this mother uses a ring from the Bayley Scales of Infant Development under the guidance of the developmental specialist. *Photo courtesy News and Information Service, The University of Texas Health Science Center at San Antonio*

Developmental milestones are recorded by the child development specialist at 6, 12, 18, and 24 months of age, referring to the "adjusted" age the child would be if birth had been at full term. The Bayley Scale of Infant Development assesses what the child can do physically such as sitting, standing, walking, reaching, and grasping. Mental development is also measured by observing how the child reacts to various events such as disappearing objects, other people, and requests by the examiner.

The assessment process serves an additional purpose, says the director. "The time required to do the Bayley testing and the intensive involvement with the child provide a setting which is conducive to the discussion of family problems, particularly as they center around the infant."

Preterm Babies of the Future

> A decade ago, 70 percent of newborns weighing less than two and a half pounds could not be saved. Now 70 percent is the survival rate. And I am not talking about damaged babies—the quality of life has improved along with the quantity of lives saved.
>
> Marilyn Escobedo, M.D.
> Neonatologist, The University of Texas Health Science Center at San Antonio

After severe illness and prolonged hospitalization, what happens to these babies who have survived? Studies show that early trauma does not necessarily lead to later disability.[2] However, when environmental conditions associated with low socioeconomic levels are present for infants already at risk biologically, the babies often show developmental delay or deficits.[3] The Mexican-American Preterm Project grew out of one neonatologist's interest in following the progress of these infants until they reach two years of age in order to find out how their early starts in life actually affect their development.

The kind of information being collected by the Preterm team will allow them to examine the relationship between the babies' medical condition at birth and during intensive care and the children's developmental progress during the next two years. It will allow them to predict how a baby—given

his or her medical history—might be expected to progress with the early, continuous, and comprehensive care the program offers. The research should help prepare parents to care for their infants and should help the clinic staff to know which conditions will require the most intensive care.

References

[1] Johnson, S. H. *High-Risk Parenting: Nursing Assessment and Strategies for the Family at Risk*. Philadelphia: J. B. Lippincott Co., 1979.

[2] Schlansker, J. T. "Developmental Follow-Up of Extremely Small Premature Infants." Paper presented at the annual convention of the Southwestern Psychological Association, Houston, Texas, April 16–18, 1981.

[3] Ibid.